

THE NEWS MEDIA AS AN AVENUE FOR INFORMING THE PUBLIC ABOUT GENETIC TESTING: WHAT MESSAGES ARE BEING COMMUNICATED?

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SIGNIFICANCE

THE NEWS MEDIA PROVIDES ONE IMPORTANT PUBLIC SOURCE OF INFORMATION ABOUT HEALTH-RELATED ISSUES. SUCH INFORMATION CAN HELP INDIVIDUALS FORM OPINIONS ABOUT THE VALUE AND RELEVANCE OF NEW FINDINGS AND INFLUENCE THEIR PERSONAL DECISION-MAKING PROCESS. AN IMPORTANT ROLE FOR THE PUBLIC HEALTH WORKFORCE AND OTHERS IS TO IDENTIFY, UNDERSTAND, AND RESPOND TO NEWS STORIES THAT MAY IMPACT HEALTH-RELATED DECISIONS AND POLICIES TO CONTINUE IN THE EFFORT TO CREATE A BETTER INFORMED PUBLIC.

RESEARCH QUESTIONS

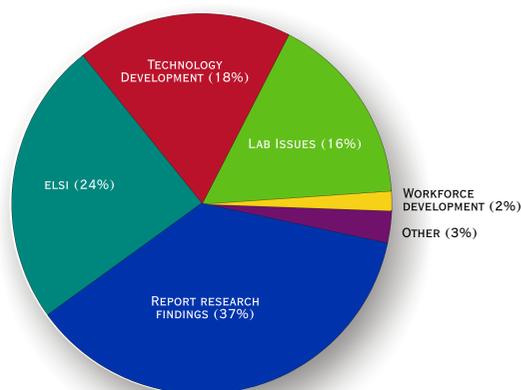
1. WHAT ARE NEWS ARTICLES DISCUSSING ABOUT GENETIC TESTING? ARE THERE GENERAL THEMES OR SPECIFIC MESSAGES BEING COMMUNICATED TO THE PUBLIC?
2. HOW IS GENETIC TESTING BEING PRESENTED TO THE PUBLIC? WHAT IS THE OVERALL TONE OF THE ARTICLES? IS THERE A BALANCED DISCUSSION OF POTENTIAL BENEFITS AND RISKS?
3. WHAT GENERAL ISSUES DOES THE MEDIA PORTRAYAL OF GENETIC TESTING RAISE THAT THE PUBLIC HEALTH WORKFORCE AND OTHERS NEED TO BE AWARE OF?

METHODOLOGY

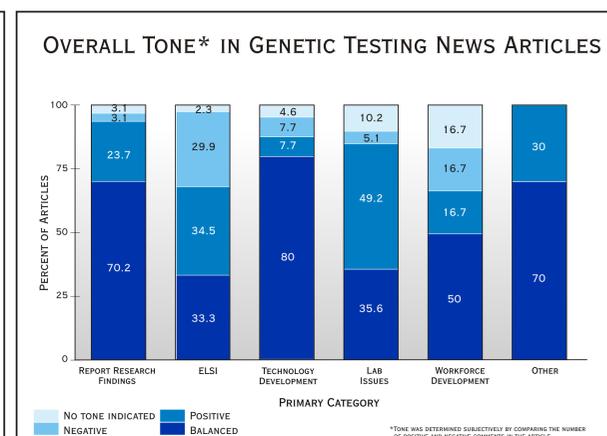
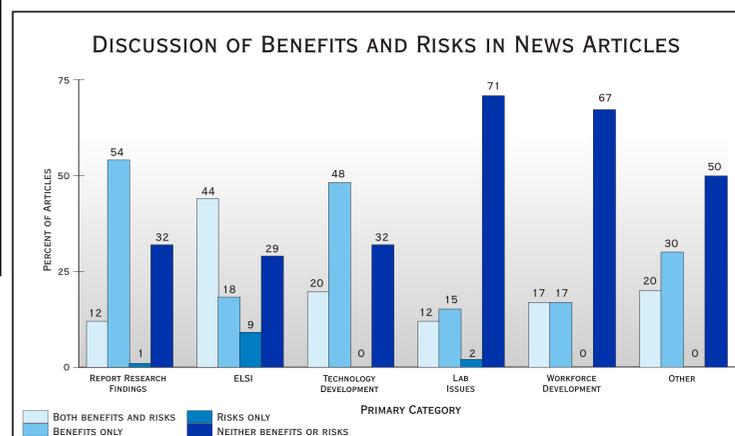
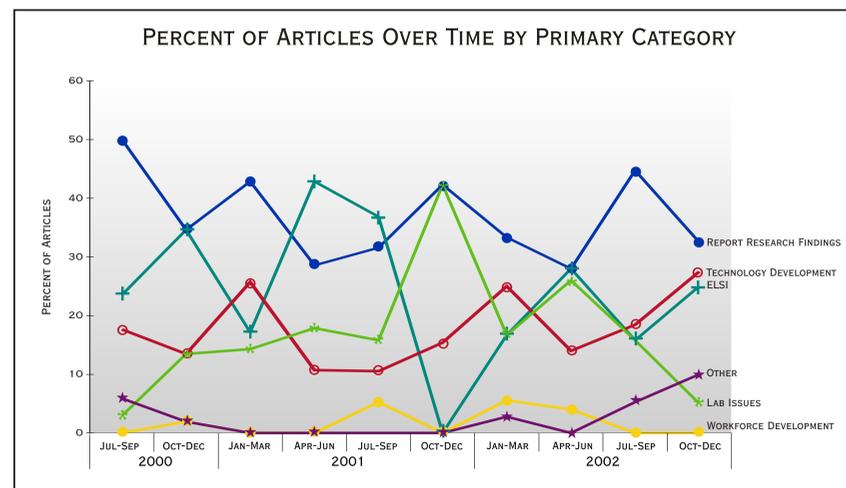
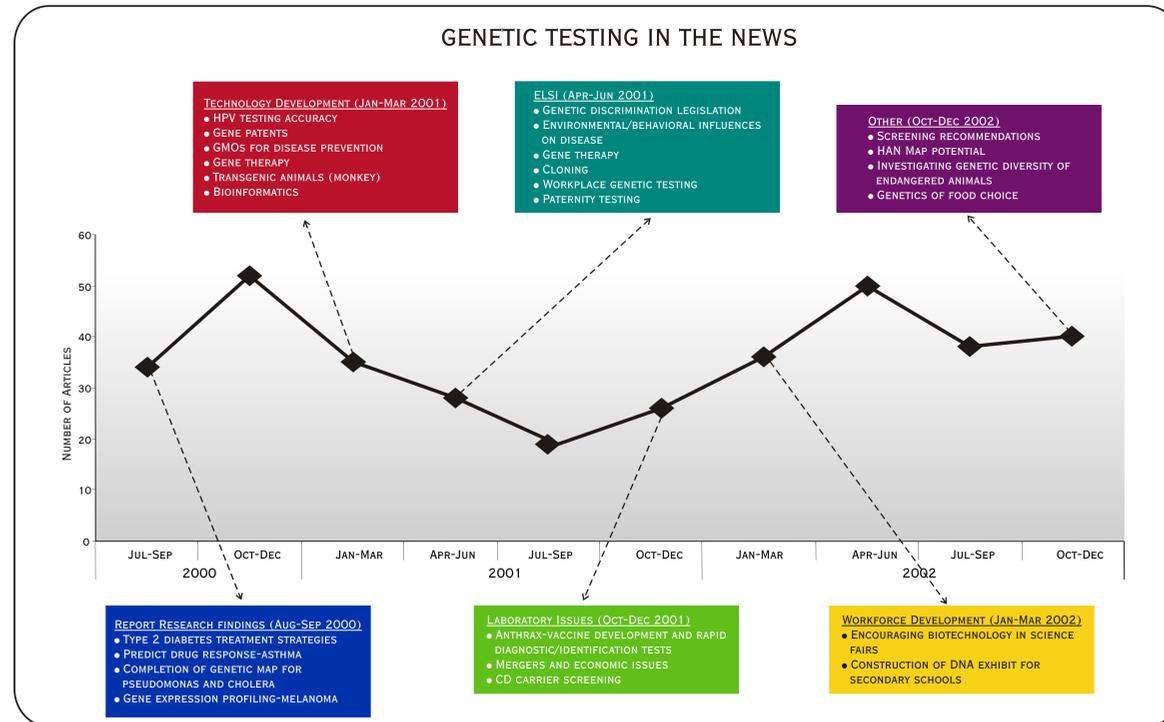
FOR THIS STUDY WE FOCUSED ON ARTICLES ABOUT GENETIC TESTING PUBLISHED BETWEEN AUG. 2000 AND DEC. 2002. SEVEN MAJOR NEWSPAPERS WERE SELECTED TO REPRESENT A NUMBER OF DIFFERENT AREAS OF THE COUNTRY: LOS ANGELES TIMES, SEATTLE TIMES, CHICAGO TRIBUNE, ATLANTA JOURNAL-CONSTITUTION, WASHINGTON POST, NEW YORK TIMES, AND THE BOSTON TRIBUNE. THE COMPUTERIZED DATABASE, LEXIS-NEXIS, WAS USED TO IDENTIFY ARTICLES. ARTICLES INDEXED UNDER THE SUBJECTS "GENETIC TESTING" BUT NOT "FORENSIC DNA" WERE INCLUDED IN THE SAMPLE. BECAUSE ONLY ARTICLES THAT HAD ALREADY BEEN INDEXED AS DISCUSSING "GENETIC TESTING" BY THE DATABASE WERE INCLUDED, IT IS POSSIBLE THAT ADDITIONAL STORIES THAT INVOLVED GENETIC TESTING BUT WERE NOT INDEXED AS SUCH MAY HAVE BEEN MISSED. ARTICLES THAT ONLY MENTIONED GENETIC TESTING IN PASSING RATHER THAN DISCUSSING IT IN ANY DEPTH OR THAT INVOLVED A BOOK REVIEW OR AN OBITUARY WERE EXCLUDED FROM THE SAMPLE. THE FINAL SAMPLE CONSISTED OF 358 ARTICLES, 17 FROM THE ATLANTA JOURNAL-CONSTITUTION, 40 FROM THE BOSTON GLOBE, 51 FROM THE CHICAGO TRIBUNE, 70 FROM THE LOS ANGELES TIMES, 62 FROM THE NEW YORK TIMES, 74 FROM THE SEATTLE TIMES, AND 75 FROM THE WASHINGTON POST.

WE ANALYZED THE ARTICLES BOTH QUALITATIVELY BY CONSTRUCTING A CODEBOOK THAT WAS DESIGNED TO CONSIDER THE CONTENT OF THE ARTICLES AND THE DISCUSSION, IF ANY, AROUND RISK, BENEFITS, AND ETHICAL, LEGAL, AND SOCIAL ISSUES (ELSI). ADDITIONALLY WE CLASSIFIED EACH ARTICLE UNDER ONE OF FIVE "PRIMARY CATEGORIES" AND IN AS MANY AS APPLICABLE OF 11 "SECONDARY CATEGORIES", WITH BOTH SETS OF CATEGORIES DETERMINED A PRIORI BY THE AUTHORS AFTER REVIEWING A SAMPLE OF RELATED ARTICLES. THE SPECIFIC TOPICS DISCUSSED WERE FILLED IN BY THE CODER. WE RATED THE TONE OF BOTH THE QUOTES AND OVERALL ARTICLE. A QUALITY ASSURANCE PROCESS WAS PERFORMED TO ASSURE CONSISTENCY OF CODING.

GENETIC TESTING ARTICLES BY PRIMARY CATEGORY
358 ARTICLES FROM AUG. 1, 2000 TO DEC. 31, 2002



DEPARTMENT OF HEALTH AND HUMAN SERVICES



DISCUSSION POINTS

THEMES/MESSAGES ABOUT GENETIC TESTING IN THE NEWS

- RESEARCH FINDINGS ARE OFTEN REPORTED IN THE CONTEXT OF A REMARKABLE FUTURE HEALTH BENEFIT.
- THE LENGTH OF TIME NEEDED TO TRANSLATE RESEARCH FINDINGS TO PRACTICAL APPLICATIONS IS RARELY DISCUSSED.
- ETHICAL, LEGAL, AND SOCIAL ISSUES (ELSI) ARE NOT ADDRESSED IN THE MAJORITY OF ARTICLES NOT CATEGORIZED IN THE "ELSI" PRIMARY CATEGORY.
- THE MAJORITY OF STORIES ARE NOT FOLLOWED OR DISCUSSED OVER TIME. RATHER, A GENETIC TESTING STORY IS FOLLOWED BY A SHORT-LIVED BURST OF ARTICLES.

TONE IN AND CLAIMS MADE BY GENETIC TESTING NEWS COVERAGE

- ELSI ARTICLES ARE MOST LIKELY TO PROVIDE A BALANCED TONE OVERALL WITH ARTICLES IN OTHER CATEGORIES MORE LIKELY TO BE OVERWHELMINGLY POSITIVE.
- OTHER ARTICLES ARE MORE LIKELY TO DISCUSS BENEFITS ONLY OR NOT MENTION EITHER BENEFITS OR RISKS.
- GENERALLY SPEAKING GENETIC TESTING, ESPECIALLY AS RELATED TO RESEARCH FINDINGS AND TECHNOLOGY DEVELOPMENT, IS PORTRAYED IN A VERY POSITIVE LIGHT WITH BENEFITS EMPHASIZED. THERE WAS LITTLE DISCUSSION ABOUT THE POTENTIAL DRAWBACKS OR DANGERS FOR DISCOVERIES AND TECHNOLOGY DEVELOPMENT UNLESS THE FOCUS OF THE ARTICLE WAS ELSI.

POTENTIAL MESSAGES TO COMPLEMENT GENETIC TESTING STORIES

- BALANCE THE PROMISE OF A NEW DISCOVERY AGAINST EFFORTS NEEDED TO TRANSLATE FINDING OR NOVEL TECHNOLOGY TO CLINICAL OR PUBLIC HEALTH APPLICATION WHILE ACKNOWLEDGING BOTH THE FINDING AND THE DESIRE FOR IT TO LEAD TO A FUTURE HEALTH BENEFIT.
- ACCURATE PORTRAYAL OF TIME BETWEEN GENE DISCOVERY AND CLINICAL OR PUBLIC HEALTH APPLICATION.
- INCREASE ATTENTION ON ELSI ISSUES WHEN ADDRESSING NEW DISCOVERIES OR PRACTICES.
- PROVIDE STRATEGIES FOR WORKFORCE DEVELOPMENT AND WAYS TO PROMOTE THESE PROGRAMS TO BRING THEM TO THE ATTENTION OF THE PUBLIC.
- EMPHASIZE WORKFORCE PERSONNEL NUMBER, TIME, TRAINING, AND RESOURCES NEEDED TO TRANSLATE NEW DISCOVERIES AND PRACTICES INTO CLINICAL AND PUBLIC HEALTH BENEFITS.

CONCLUSION

WITH A BETTER UNDERSTANDING OF HOW GENETIC TESTING IS BEING PORTRAYED BY THE NEWS MEDIA, PUBLIC HEALTH AND OTHERS CAN IDENTIFY OPPORTUNITIES TO BE INVOLVED IN THE EFFORT TO INFORM AND EDUCATE THE PUBLIC. PROVIDING A BALANCED AND REALISTIC VIEW OF THE BENEFITS AND TRANSLATION OF GENETIC DISCOVERIES INTO PRACTICE MAY BE ONE AVAILABLE AVENUE. CONSTRUCTING MESSAGES COMPLEMENTARY TO AND WORKING WITH THE NEWS MEDIA TO ASSURE THAT SUCH ACCURATE AND BALANCED INFORMATION IS BEING PROVIDED WILL HELP TO CREATE A MORE INFORMED PUBLIC.

ELSI DISCUSSION BY PRIMARY CATEGORY

